

This is a section of [doi:10.7551/mitpress/14152.001.0001](https://doi.org/10.7551/mitpress/14152.001.0001)

# **Kids Across the Spectrums**

## **Growing Up Autistic in the Digital Age**

**By: Meryl Alper**

### **Citation:**

*Kids Across the Spectrums: Growing Up Autistic in the Digital Age*

**By: Meryl Alper**

**DOI: 10.7551/mitpress/14152.001.0001**

**ISBN (electronic): 9780262374002**

**Publisher: The MIT Press**

**Published: 2023**

The open access edition of this book was made possible by generous funding and support from MIT Press Direct to Open



**The MIT Press**

# 1 INTRODUCTION

In 1959, an article titled “Joey: A ‘Mechanical Boy’” appeared in the popular science magazine *Scientific American*.<sup>1</sup> It was written by the influential child psychologist Bruno Bettelheim, who at the time was the director of the Orthogenic School of the University of Chicago. Bettelheim’s career and reputation were built on his work with children at the school who, like Joey, were on the autism spectrum, which was known in the scientific community at the time as childhood schizophrenia. In his *Scientific American* piece, Bettelheim frames the story of Joey as a cautionary tale: “a case history of a schizophrenic child who converted himself into a ‘machine’ because he did not dare be human.”<sup>2</sup> Bettelheim claims that in his daily life, Joey adopted the persona of a robot that rejected human feelings and that his pathology was caused by his supposedly unloving parents. Joey also drew pictures of himself, featured in the piece, full of wireless controls and electrical circuits. Using these self-portraits and his notes on Joey’s treatment, Bettelheim crafts a therapeutic narrative in which Joey “ceased to be a mechanical boy and became a human child” by the end of his treatment with Bettelheim; the psychologist treated Joey when he was between 9 and 12 years old.<sup>3</sup>

Bettelheim would later come to prominence as a public intellectual for his 1976 book *The Uses of Enchantment*, which argued that fairy tales were important for children’s development because the dark and fantastical stories allowed them to grapple with complex emotions.<sup>4</sup> In the years since his passing in 1990, however, Bettelheim’s work has received significant rebuke. The criticism includes claims that his academic credentials were fraudulent, that he abused patients under his care, and that his theories of the causes of

autism were wrong.<sup>5</sup> Yet the dominant and dehumanizing image of the autistic mechanical boy persists in the public eye and in popular culture. Through his own fantastical, dark telling of Joey's story, Bettelheim perpetuated the idea that autistic children are inherently mechanical in their thinking and behavior, functioning "as if by remote control."<sup>6</sup>

The notion that kids on the spectrum prefer technology over human interaction has taken many shapes in mass media. News reports falsely imply a link between autism, violent video games, and school shootings, as well as associate people on the spectrum with criminality.<sup>7</sup> In a much milder version of the mechanical-boy stereotype, autistic youth are assumed to have a natural affinity for technology. This belief underpins investments in social therapy robots and in workforce training programs in the high-tech sector, which are designed primarily to capitalize on autistic children's purported penchant for detail and preference for repetition.<sup>8</sup> The trope of mechanized children is also reflected in anxieties that mobile devices and new media rewire the brains of neurotypical young people (i.e., those whose intellectual and cognitive development is considered normative), allegedly reducing empathy, causing the avoidance of eye contact, and rendering them unable to handle spontaneous social interactions.<sup>9</sup> At its most alarmist and panic-stricken, such rhetoric warns of screens inducing an "epidemic of cultural autism."<sup>10</sup>

Since the publication of "Joey," other forms of misinformation about autism have proliferated, including the dangerous claim that it is caused by childhood vaccination.<sup>11</sup> Though the exact neurological and genetic basis of the condition is unknown, autism is, in the broadest possible terms, a cognitive, biological, and behavioral phenomenon that influences how people move, think, and perceive the world around them.<sup>12</sup> Some people on the autism spectrum are very talkative, while others may be unable to reliably communicate through oral speech. Some are intellectually gifted, while others have significant cognitive challenges. Some autistic individuals are highly sociable, while others prefer greater solitude.<sup>13</sup> These qualities and abilities are variable and can fluctuate over the years or depending on the day. People are born autistic and remain so throughout their lives, though there is far more research on children than on adults. Individuals today are far more likely to personally know someone who is on the spectrum than they did when "Joey" was first published. This is for a multitude of reasons, including disability activism in the late twentieth century that pushed for the closure

of inhumane institutions housing disabled people and for their fuller community integration.<sup>14</sup>

This book invites a retelling of history that centers on Joey's story instead of Bettelheim's version. The reductive and overly simplistic characterizations of young people on the spectrum, their technology use, and associations between autism and media present a paradox because, in actuality, there is very little real-life research on the media environment that surrounds autistic children into which any new technological innovation or intervention would presumably enter. Nor has much work chronicled the digital experiences of children on the spectrum who might otherwise contend with major opportunity barriers to social and digital inclusion based on their race, ethnicity, class, or gender.<sup>15</sup> Beyond Joey's beloved circuits and controls, the persuasive and appealing design of new media may also uniquely interact with the social, behavioral, and communicative characteristics of autism and neurodivergence in both positive and negative ways.<sup>16</sup> I set about working on this book to reconcile how neurotypical people could talk with such authority about the relationship between autism, children, and technology without a strong empirical basis to their claims, and to remediate some of the harms done to autistic people by the perpetuation of these myths.

*Kids Across the Spectrums* critiques and complicates stereotypes about "mechanical boys" by presenting the first book-length study of autistic young people and their everyday uses of media and technology. From 2013 through the beginning of the coronavirus pandemic in 2020, I conducted in-depth qualitative research in the homes of more than sixty children, ages 3 to 13, in Boston and Los Angeles. This diverse group comprised young people of many races, ethnicities, socioeconomic classes, and genders, for there are "Joeys," but there are also "Josephines" and "Josefinas." The work was informed by the multiple ethical, communicative, and practical considerations of conducting ethnographic fieldwork with speaking and nonspeaking autistic young people.<sup>17</sup> I interviewed adolescents about their media likes and dislikes, consulted with caregivers about their hopes and concerns about screens, and observed autistic children at home engaging in their favorite media activities. This included playing video games with their parents, chatting with their friends on FaceTime, and making YouTube videos with their siblings. Executing this research over the past decade, I focused less on passing technological trends and more on patterns that consistently emerged in the narrative accounts of autistic children and their loved ones.<sup>18</sup>

I found that what kids on the spectrum are doing with media is not necessarily radically different from what the nonautistic population of young people are doing. Indeed, prior research has shown that autistic children's overall time spent with media on average may be on par with the time spent by neurotypical school-age kids.<sup>19</sup> However, the experiences that children on the autism spectrum have with technology are less explained by their diagnoses alone and more by the intersections of their disability with other aspects of their identity and the modern conditions of childhood. They differentially face significant social and health inequalities—including limited recreational programs, poor neighborhood safety, and challenges receiving appropriate therapeutic services—and I argue that these disparities spill directly over into autistic children's media habits.

Employing a grounded theory approach, in which participant data is used to develop explanatory insights from the bottom up,<sup>20</sup> I identified three overlapping areas of autistic children's successes and struggles with technology that I explore in this book: *cultural belonging*, *social relationships*, and *physical embodiment*. This project documents the marginalization that technology can compound while highlighting the strengths that autistic young people bring to digital media and the unique opportunities that they find there for social connection, communication, and creativity.

## THE SOCIOTECHNICAL SHAPING OF SOCIALITY

While this book chronicles the mediated lives of individual autistic children, the stories of these young people are linked together. Furthermore, how their stories are connected has to do with much more than just their or their family members' singular experiences. Sociologist C. Wright Mills used the term "sociological imagination" to describe the ability to identify relationships between personal biography and larger social realities.<sup>21</sup> Social science theories help us explain those associations, identify specific phenomena, and enhance public understanding. In this book, I draw on a range of theories from several relevant academic fields, such as sociology, child development, and science and technology studies (STS). I critically reimagine these ideas in new and practically useful ways based on my conversations and observations, and additionally through the lenses of disability and autism.

Research in the field of communication studies—my primary academic discipline—increasingly explores the role of new media in the lives of

marginalized groups and how technology can both ameliorate and contribute to their invisibility, exclusion, and misrepresentation. Disability and its connections to social, cultural, and political life though are little understood, with notable exceptions.<sup>22</sup> This omission not only masks the multifaceted ways that disability intersects with other dimensions of human difference, but also dislocates disabled people from important theoretical and conceptual debates. For, as historian Katherine Ott writes, “Disability is unique in the extent to which it is bonded with technology, tools, and machines as a medium of social interaction.”<sup>23</sup> This book extends an analysis of technology and marginality that I examined in my last book, *Giving Voice*.<sup>24</sup> That project centered on how nonspeaking children with disabilities (primarily autism) used Apple iPads as assistive speech aids, otherwise known as augmentative and alternative communication (AAC) devices, and the extent to which those technologies gave them a metaphorical and literal voice.

Considering the multimedia potential of the iPad, I became interested in everything else that autistic kids were doing with digital devices. Ethnographers have illustrated the value of media in children’s lives and how racially and ethnically marginalized youth navigate this landscape,<sup>25</sup> but they have rarely focused on disabled children.<sup>26</sup> While their preferences for media platforms and activities do not diverge significantly from those of their nonautistic peers (e.g., television, YouTube), autistic children’s motivations for seeking out certain content can vary; for example, they may be seeking sensory stimulation or emotional comfort.<sup>27</sup> Children on the spectrum are also reportedly more likely than nonautistic youth to engage in excessive media use, with possible negative health effects including sleep disruption, increased sedentary activity, and decreased exercise—all of which has been exacerbated by the COVID-19 pandemic.<sup>28</sup> Yet the evidence for these outcomes is often incomplete and decontextualized from daily life. Most published research is based on parent surveys, focus groups, or phone interviews that oversample White, educated, upper-middle-class mothers of boys.<sup>29</sup> Reflecting other sociological work on the geographies of youth,<sup>30</sup> this book fills a gap by directly engaging diverse autistic children in conversations about their media use from within in their home environments, where they spend the most time with technology.

This book also builds upon theories from the academic field of STS, which looks to examine the historical, sociocultural, and political context of the development and impacts of science, technology, and their entwinement

(i.e., the sociotechnical). Since the beginnings of the field's existence, there has been an awareness of how disability and disabled people complicate linear, progress-oriented narratives of technological innovation and scientific discovery.<sup>31</sup> With respect to autism, there is a burgeoning scholarly space in STS for examining how biomedical discourses construct the condition as a social category.<sup>32</sup> Autism, for instance, has long been employed as a cultural metaphor to describe self-isolation and a personal tendency toward aloneness.<sup>33</sup> This pathologized framing is rooted in a prescriptive, neurotypical understanding of what ideal sociality and communication should be like. Less attention has been paid, though, as to how ideas about autism shape popular technological discourse itself, or as disability studies scholars David Mitchell and Sharon Snyder note, how “disability underwrites the cultural study of technology *writ large*.”<sup>34</sup>

In this book, I argue that the technological experiences of autistic children underscore the intricacies, anomalies, and expectations of the socially mediated world, or what I term “the sociotechnical shaping of sociality” (STSS). Sociologist John Law notes that “the social is not purely social at all” because society is also structured by technology.<sup>35</sup> But what it means to *be* social—to possess social skills, interact socially, and have meaningful relationships—also does not exist outside of the affordances and constraints of technologies for enacting sociality, nor is it beyond social stigmatization and the boundaries of society more broadly. For instance, as part of the iOS 14 software update in 2020, Apple added the Eye Contact function to its FaceTime video chat app. According to the company, the new feature “uses machine learning to subtly adjust the position of your eyes and face to make video calling more natural even when you’re looking at the screen instead of the camera.”<sup>36</sup> The fact that Eye Contact is enabled by default on the iPhone highlights the subtle ways in which neurotypical social norms become embedded in design. While a non-autistic person might not notice any differences in their communication as a result of Eye Contact being turned on, autistic people commonly report that making eye contact feels unnatural to them and that forced eye contact with others is painful and anxiety inducing.<sup>37</sup>

In my development of STSS, I draw on what cultural anthropologists Elinor Ochs and Olga Solomon term “autistic sociality” to convey how the set of social repertoires that autistic people work from, like preferring to avoid direct eye contact in conversation, is one of many valid, not lesser, possibilities for being social.<sup>38</sup> Implicating autism in the complexity of that which

is sociotechnical disrupts the use of autism as a symbol through which rigid and oppressive normativity is reinforced.<sup>39</sup> Even to Bettelheim, Joey's case was about more than any one child. "His story," Bettelheim wrote, "has a general relevance to the understanding of emotional development in a machine age. . . . [Our] society of mechanized plenty often makes for [difficulties] in a child's learning to relate."<sup>40</sup> The tale of Joey, Bettelheim writes, is one of humanity triumphing over machines.

It is a tale, I contend, that needs to be retold, and by people besides just myself. The more that researchers and lay individuals learn about autism, the more challenging it becomes to summarize or universalize. One reason for this is that the story of disability has historically been told by those without disabilities.<sup>41</sup> People on the spectrum (who themselves vary vastly in their opinions and beliefs) are increasingly taking discursive ownership through autistic autobiography, or what rhetorician M. Remi Yergeau terms "autie-biography."<sup>42</sup> Because of this, it is important to note early on that I do not identify as autistic, nor do I have a close family member on the spectrum. I rigorously approach critical questions of disability and communication technology through the theoretical lens of an academic committed to equity, and in applied contexts as an educational researcher who has worked over the past 20 years to make inclusive and accessible learning products with media organizations such as Sesame Workshop, Nickelodeon, and PBS KIDS. Considering my focus on inequalities, it is also relevant to share that I am an upper-middle class, White-appearing, English-speaking, straight, and cisgender woman who has benefitted from privileges produced by these distinctions in a contemporary US context.<sup>43</sup> In *Kids Across the Spectrums*, I incorporate the research of autistic scholars who address autism and neurodiversity from a variety of disciplinary, theoretical, and methodological perspectives, as well as the writings of a diverse group of disability activists, journalists, and youth regarding their experiences with media, technology, and marginalization.<sup>44</sup>

In the following pages, I build a case for STSS, first by reviewing the literature on autism and the contested framing of autistic people's sociality—and effectively, their humanity. I then discuss how the power to deem certain technologies or technological usage "social" and the conditions under which this is done is rarely in the hands of autistic people, although these dynamics are gradually shifting, especially for youth as they employ digital and social media to share their unique viewpoints.<sup>45</sup> Next, I turn toward young people on the autism spectrum and the varied ways in which



“social technologies” shape their lives. Lastly, I detail the complexity of “the spectrum” in the context of autism, media, race, and socioeconomic status, and conclude with an overview of this book and a summary of subsequent chapters. I begin now with a discussion of how media, technology, and sociality can take on a range of domain-specific meanings for autistic young people, illustrated by Adrian’s story in the next section—which I should note for readers contains discussion of physical victimization and emotional trauma, all too frequent occurrences for autistic individuals (see also the beginning of chapter 7).<sup>46</sup>

### “IT’S TURNED INTO MORE OF A SOCIAL MEDIA WEBSITE FOR ME”

I interviewed 13-year-old Adrian, a White autistic boy, in his dimly lit living room in the Boston suburbs while he nestled into an overstuffed chair, his auburn curls peeking out from the sweatshirt hood that he kept up for much of interview.<sup>47</sup> His mom, Brianna, referred to Adrian as “an Aspie,” referencing an Asperger’s syndrome diagnosis that he had received before it fell under the umbrella of autism in the fifth edition of the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), which is used by clinicians to diagnose the condition. Brianna noted that her husband, Adrian’s father, Stewart, “would say he has Aspie-like qualities” as well. When I asked Adrian what he most liked to do on the computer, he brought up Scratch, a kid-friendly computer programming website and online community developed by researchers at the Massachusetts Institute of Technology for children to share and remix projects that they code and design. I was perplexed, however, when Adrian referred to the website as “social media,” a label that seemed more fitting for the mobile apps Instagram or Snapchat, neither of which he used. “Scratch was originally meant to be a ‘share what you have learned’ type of thing, but people have turned it into a really active social media page,” he said.

Adrian had started using Scratch at age 7 and enjoyed making “slightly buggy, really large, fun games.” Lately though, he had been using the studios feature on the website (i.e., collaborative pages where different users can put multiple coding projects) to engage in a role-playing game in which players use the Comments section to discuss characters that they and others create. “It’s turned into more of a social media website for me instead of just a normal coding website,” Adrian said of this activity. He described

a constant flow of users commenting on one another's content and receiving notifications that he would sometimes check on his phone during class if he finished a test early. "People have learned how to turn this into like pretty much automatic chatting where you can keep up with people almost instantly," he said. Outside of Scratch, Adrian rarely texted people and preferred to talk on the phone with friends from school or his weekly Pokémon League gaming meetup. He did belong to Amino, a social networking app for anime fans, but used it more for consuming content than receiving follows and comments. Said Adrian, "I still check [Amino] every day just to see what new art there is, but I don't use it as social media anymore."

Adrian's reflections on the social adaptability of Scratch and his selective use of social media for interpersonal purposes reminded me of a long history of the co-optation of new communication technologies, personal definitions of the "social" in social media, and instances of platforms being appropriated for uses beyond those intended by their original designers.<sup>48</sup> Consider those on Tinder who use the dating app in an "off-label" way to professionally network instead of meeting romantic partners.<sup>49</sup> The landline telephone was eventually used as means of social connection and conversation, but only after it was initially advertised for business and household management.<sup>50</sup> Scratch already invites such ambiguity of use<sup>51</sup> as both a computer programming tool and online community. Adrian and his fellow users had turned the message boards of a website dedicated to designing games into a role-playing game itself.

His engagement with Scratch also speaks to larger issues of cultural norms, social power, and technological agency. Adrian's digital media use occurred against the offline backdrop of peer bullying, which started for him in fifth grade, the year he began attending the same arts-focused charter school as his older brother, Marco. Brianna and Stewart hoped the more creative environment would be a better fit for Adrian than the sports-oriented public schools in their town. The charter school, however, did not provide him with any of the support services for his autism, anxiety, and dyslexia that were detailed in his Individualized Education Program (or Plan) (IEP), a legal document outlining how a child's specific learning needs will be met in the US education system. The school's failure to adhere to the IEP came to a head one day when Adrian placed his hands on a desk near another girl in his class. She asked him to move and when he did not, she responded by stabbing him with a pencil, to which he reacted by hitting her.

While the girl was not punished—an outcome perhaps less likely if her victim had not been autistic—Adrian was suspended from school for two days. Though Adrian was only 10 years old at the time, the girl’s father also decided to press charges with the police. To make matters worse, when Adrian returned to school, a group of older boys cornered him on the playground and told him to “fight like a man.” Brianna worried that if the abuse continued, Adrian would end up in a residential treatment program or harming himself. After the incident, the girl’s parents said that they would drop the charges if Brianna and Stewart pulled Adrian out of school, which gave them the impetus to leave. She and her husband subsequently enrolled him in a private school for students with learning disabilities. His tuition was funded under Massachusetts’s Chapter 766 law, which guarantees the rights of all young people with disabilities to an educational program best suited to their needs.<sup>52</sup>

Throughout Adrian’s traumatic and turbulent experience, he was systematically isolated while simultaneously denied the opportunity to build social and emotional competencies. What he underwent emphasizes how disability and impairment are intertwined,<sup>53</sup> as it is difficult to disentangle the social traumas that intensified Adrian’s autism-related challenges from the impact of being stripped of his entire social world because he was autistic. In programs at his new private school and through counseling outside of school, Adrian worked on social pragmatics (i.e., the language one uses in social situations) or what his family referred to as “keeping your shit together.” He put significant effort into emotional regulation and managing his frustration. The training that Adrian received was bound up with his desire to connect with others around him and through media. Brianna noted how playing video games at home with Marco and his friends motivated Adrian to keep himself levelheaded as to not embarrass himself in front of the older boys. “If he gets frustrated playing a game, he has learned that he can’t slam the door to his room and throw stuff around because people will hear that,” said Brianna, “so he will quietly walk up the stairs and lay in bed and read if he’s had enough.”

Technological and creative play were central to Adrian’s forging of social bonds. Referencing his reading challenges, he said that Scratch was “great for me and many other kids because it usually says outright what the block does . . . it’s a way easier type of code for me to understand.” He had “lots of story ideas” for Scratch and showed me one such animated clip he had

made that reminded me of an artsy indie film, in which an elevator door opened and closed on different scenes. Adrian's technical skills were also opening doors for him professionally, so to speak. After attending a Scratch camp where he excelled at helping younger campers, he got offered a part-time job mentoring kids at a different computer camp with their projects on Minecraft, another digital game space for creative worldbuilding. "I'm really glad that I'm starting now," Adrian said about the job, "because I was getting concerned like oh, you know, I'm starting slow," reflecting a pressure commonly felt by US teens to start their professional advancement early. Far from retreating into the digital world, Adrian's rich involvements with Scratch and Minecraft were an important social bridge to new participatory prospects.

## DEFINING AUTISM

It is important to contextualize Adrian's choice of words to socially classify networked technologies. He was someone who not only eschewed what might traditionally be thought of as social media, but a person who was clinically characterized as lacking sociality by virtue of his diagnosis. No test like blood samples or a brain scan can diagnose autism; doctors instead rely on behavioral observations and caregiver reports. "Infantile autism" was first recognized as a clinical diagnosis in the United States in the third edition of the DSM within a class of several "pervasive developmental disorders."<sup>54</sup> Along with the World Health Organization's International Classification of Diseases (ICD-11), released in 2018, the revised DSM-5 outlines various criteria for making an autism diagnosis.<sup>55</sup> It defines the condition as a spectrum of closely related disorders that present as "persistent deficits" in an individual's development of social relationships, as well as "restrictive, repetitive" patterns of behavior, interests, or activities. However, diagnostic manuals are not politically neutral tools, as they have historically been wielded in unjust ways.<sup>56</sup> For example, homosexuality was pathologized in earlier editions of the DSM.<sup>57</sup> Childhood schizophrenia was phased out as a diagnosis—a change though that was motivated by a racist and racialized desire to distinguish White "autistic children" from Black "childhood schizophrenics."<sup>58</sup>

Defining autism exclusively through the lens of diagnostic manuals like the DSM fits into what is known as a medical model of disability, in which disability is located biologically within the individual.<sup>59</sup> The aim of

therapeutic interventions and research supported by this model is to prevent, diminish, or correct for a disability. In the case of autism, this medicalization regularly manifests in language used to describe increasing rates of autism diagnoses as a “crisis” or as a “disease” in need of a “cure.”<sup>60</sup> Many in the autism community find this rhetoric and media coverage harmful because it characterizes autistic people as a burden and rationalizes violence against them.<sup>61</sup> This perspective may have also contributed to the ableism that Adrian experienced in school. The material and symbolic environment around an autistic person (e.g., the laws and policies shaping Adrian’s education) can also significantly restrict and limit their abilities, reflecting a social model of disability that shifts emphasis away from the individual and toward the stigmatizing effects of society. Another formulation, the political/relational model of disability,<sup>62</sup> recognizes gaps in both models for overlooking the collective strengths and pleasures of being disabled.<sup>63</sup> For example, Scratch hosts several animated videos made by autistic children discussing and explaining proudly what their autism means to them.<sup>64</sup>

In their everyday lives, kids on the spectrum encounter challenges across their individual, social, and political contexts, and these obstacles are shaped by the fact that neurotypical communication and movement is the dominant cultural standard. In terms of interaction with nonautistic people,<sup>65</sup> these challenges can include back-and-forth conversation, understanding emotional intention and nonverbal communication, and expressing oneself with language.<sup>66</sup> Behaviorally, autistic children may have difficulties with executive functioning, including planning ahead, handling changes to routines and transitions between activities, and dealing with sensory input sensitivities.<sup>67</sup> Autistic children are regularly victims of bullying and social exclusion.<sup>68</sup> But life is not always a struggle, and there are unique assets that autistic children may have as well. For example, some learn to read at an early age (or what is known as hyperlexia).<sup>69</sup> Cognitively, strengths can include visual pattern recognition, attention to detail, rule-based thinking, and rote memory. Some have a keen sense of humor, especially when it comes to jokes that defy logic and expected setups.<sup>70</sup>

The terms for referencing autism are also far from straightforward. The medical field largely uses “autism spectrum condition” (ASC) or “autism spectrum disorder” (ASD), and accordingly, “person with autism/ASC/ASD.” Parents and clinicians tend to prefer using “person with autism,” which in disability parlance is known as “person-first” language, over “autistic”

or “autistic person,” which is referred to as “identity-first” language. Some would argue, however, that the phrase “person-first” has more to do with word order than necessarily putting people first in the sense of prioritization. Autistic adults generally favor “identity-first” language, reflecting the idea that their autism is an inseparable part of who they are, though this varies culturally.<sup>71</sup> Using “person with an autism diagnosis” as an alternative is complicated because not everyone who would meet the criteria for a diagnosis is able to get one. Being diagnosed is distinct from culturally identifying with autism, as in the shared rituals, language, and art that produce common meanings among autistic people.<sup>72</sup> This is particularly true for autistic adults, many of whom did not receive formal diagnoses as children or for various reasons have not sought one out as an adult, such as Adrian’s father.

Another common and perhaps more neutral diagnostic term is being “on the autism spectrum,” a concept introduced by Lorna Wing, a medical researcher and parent of an autistic child.<sup>73</sup> The word “spectrum” is meant to symbolize many things: that autism is more like multiple related conditions than a single one; that these conditions can be expressed in myriad ways; and that there are many possible life trajectories for a person with an autism diagnosis. However, as continuums have beginning and end points, this language may also reinforce the idea of a hierarchy of abilities, whereby some are deemed “low” or “high” functioning.<sup>74</sup> These terms are controversial within the autism community because they create a binary and can end up minimizing the struggles of people considered high functioning and minimizing the strengths of people considered low functioning. Science journalist Steve Silberman points to multiple clusters instead of a single linear spectrum, noting that autism “[produces] a distinctive constellation of behavior and needs that [manifest] in different ways at various stages of an individual’s development,”<sup>75</sup> a perspective that I adopt in this book.

## AUTISM AND SOCIALITY

Clinical autism research focuses primarily on evaluating an autistic individual’s one-on-one social competencies, and less so on the effects of social life and cultural expectations in their groups and communities.<sup>76</sup> Cognitive theories have dominated autism research with little attention paid to how social contexts shape understandings and experiences of autism; hence, ethnographies like this book are quite rare. The prefix “aut” in autism comes

from the Greek word *autós*, meaning “self.” The term “autism” was coined in 1911 by German psychiatrist Eugen Bleuler to describe people who he believed had an inner life not readily accessible to others.<sup>77</sup> In the early 1940s, Leo Kanner was the first scientist to publish research on infantile autism,<sup>78</sup> which had a significant impact on the development of the DSM. The DSM-5 includes diagnostic criteria such as “deficits in social-emotional reciprocity” (i.e., social interaction), “deficits in nonverbal communicative behaviors used for social interaction” (i.e., social communication), and “deficits in developing, maintaining, and understanding relationships” (i.e., social imagination).<sup>79</sup>

The wide assumption of preferred solitude among those on the autism spectrum is currently undergoing resistance and revision by psychologists, anthropologists, and autism self-advocates.<sup>80</sup> They contend that the social motivations of autistic people do not rest solely within the diagnosed individual but arise from dynamic interactions and relationships in specific contexts over time.<sup>81</sup> For example, in a much commented-upon 2019 article in the academic journal *Behavioral and Brain Sciences*, psychologists Vikram Jaswal and Nameera Akhtar argue that people on the spectrum *appearing* socially uninterested is not the same as them actually *being* socially uninterested.<sup>82</sup> Perceptions of autistic people’s social behaviors are influenced by how others (particularly those who are nonautistic) interpret their expressions of social interest.<sup>83</sup> Being understood as having strong interpersonal abilities depends on how both society and technologies designate someone as a social person, subjective determinations that are influenced by perceptions of disability as well as race, ethnicity, class, gender, and sexuality.<sup>84</sup>

Proponents of neurodiversity, a term coined by sociologist Judy Singer and popularized by journalist Harvey Blume,<sup>85</sup> argue that neurological differences impacting learning, attention, and other cognitive functions are authentic forms of human diversity (conditions including but not limited to autism, such as attention-deficit/hyperactivity disorder [ADHD]). They challenge the idea that neurodivergent people should be forced to socially conform to a neurotypical ideal.<sup>86</sup> Neurodiversity is both a philosophy centered on acceptance and a movement focused on access to needed supports and accommodations. Through the lens of neurodiversity, autistic education scholar Damian Milton contends that instead of individuals on the spectrum not being able to see the perspectives of others, it is neurotypical people who have a “double empathy problem” by being unwilling to empathize with those who are autistic.<sup>87</sup> Far

from isolated in their own worlds, autistic people often have a deep sense of morality and are finely attuned to various forms of social injustice.

Within the fields of sociology and anthropology, flexible interpretations of social interactions have only recently been extended to individuals on the spectrum. Georg Simmel, one of the first sociologists to study sociality, described sociability as the urge to associate with others for the sake of associating and as an essential part of society.<sup>88</sup> However, the impulse to engage in small talk, for example, is not universal. Ochs and Solomon offer autistic sociality as a concept that describes a form of sociality shared by autistic individuals that is not quantitatively less social than the form preferred among nonautistic people, but instead qualitatively different.<sup>89</sup> Human sociality encompasses a range of possibilities for social coordination shaped by situational contexts, materials, and the dynamics of groups and individuals, with autistic sociality being one such permutation. For instance, people on the spectrum report that they find very satisfying companionship in nonhuman entities like animals, objects, and even their own bodies.<sup>90</sup> In his memoir, penned when he was 12 years old, the autistic author Ido Kedar writes that he treats self-stimulatory behaviors such as flapping his hands “like a welcomed friend because they are really with me all the time.”<sup>91</sup>

Ochs and Solomon distinguish between the social that is interpersonal and the social that is sociocultural, while recognizing their co-constitution. For example, the ability of autistic people to navigate conversational rules and norms of social behavior depends a great deal on the normative and neurotypical structures of society. Anthropologist Ben Belek, in his ethnographic study of autistic university students, draws attention to “the creative technologies people design when typical responses to social rules remain out of their reach.”<sup>92</sup> Marginalized social groups may internally develop “alternative techniques of social proficiency” when expected social rules are “inherently inaccessible”<sup>93</sup> to them. For example, when autistic people began to organize Autreat, a retreat-style conference, in the 1990s, they developed a color-coded communication system using red, yellow, and green badges to indicate personal willingness to be approached for conversation.<sup>94</sup> In his use of the term “creative technologies,” Belek refers to *techne*, which is the Greek root of “technology” and means the capacity for humans to transform their abilities and the world.<sup>95</sup> Remaking the social world through code and craft is essentially something that autistic people and individuals with disabilities are well equipped to do.<sup>96</sup>



## AUTISM AND THE SOCIOTECHNICAL SHAPING OF SOCIALITY

Autistic people provide at once unique and undervalued insights into research on technology and society that speak to both specific and broad experiences of marginalization. They have much to add as a group whose interpersonal relations have long been mediated by the internet because of stigma, bias, and discrimination.<sup>97</sup> New media—for example, social media hashtags on Twitter such as #ActuallyAutistic, #AskingAutistics, and #BlackAutisticLivesMatter—have made visible a wider range of social identities and intersectionality that exist around being autistic and has helped connect people on the spectrum with one another despite the physical distance between them.<sup>98</sup> Online spaces have certain affordances—such as the removal of facial cues, asynchronous conversation, and the ability to pause for breaks—that allow many on the spectrum to communicate with both neurotypical and neurodivergent individuals in a more natural and pleasurable way.<sup>99</sup> That autistic people develop community online runs counter to the asocial diagnostic classification of autism. Social norms and perceptions of sociability are both created and contested by autistic people through digital technology.

This negotiation illustrates the sociotechnical shaping of sociality, or, in more formal terms, the interrelation of technology, society, and social norms across mutually dependent macro-level institutions and micro-level interactions. Feminist approaches to STS have critiqued histories of technological development that lend too much power to scientific and technical experts when marginalized social groups, including disabled people, are actively excluded from participation in those processes.<sup>100</sup> STS has also inadequately accounted for autism and neurodiversity in theorizing the relationship between human and technological trajectories, with some perpetuating the claim that autistic people are “are born without socialness.”<sup>101</sup> In recent years, this has been contested by feminist STS scholars such as Jessica Rauchberg, who call for neurodivergence and neuroqueer technoscience to more richly inform the development of information and communication technologies. These scholars draw on the concept of “crip technoscience,” proposed by disability scholars Aimi Hamraie and Kelly Fritsch, in order to center disabled knowledge production within the social study of technology.<sup>102</sup> STSS is most directly derived from the social shaping of technology approach in STS,<sup>103</sup> which deconstructs how technology enables certain societal opportunities while society and social actors (e.g., developers, users) generate

different technological options, with neither being predetermined.<sup>104</sup> For autistic young people, this means that the living, socializing, and coping mechanisms available to them and their families are shaped by the media platforms at their disposal, which children like Adrian also fluidly co-opt for different social purposes.

STSS generates broader questions beyond autism about how both interpersonal and sociocultural dynamics shape and are shaped by technology, with particular attention paid to those individuals who find dominant social rules to be uninterpretable or social spaces to be inaccessible. For example, Sara, mom of 8-year-old Isaac (a nonspeaking White boy with communication and sensory processing challenges) noted that “he watches YouTube all the time. I feel like socially he gets this whole other aspect of this whole other world that maybe he wouldn’t be able to access.” Experiencing sociotechnical inaccessibility can itself generate meaningful social processes and new technological possibilities. By centering autism and the perspectives of autistic people in the study of technology, society, and sociality, STSS responds to Mara Mills and Jonathan Sterne’s call for “dismediation,” which prompts a rethinking of media theory through disability theory, or, in other words, understanding “disability as a constituting dimension of media, and media as a constituting dimension of disability.”<sup>105</sup>

Additionally, STSS builds upon work in communication studies and media sociology that challenges the presumed superiority of physical, face-to-face contact,<sup>106</sup> as well as questions the taken-for-grantedness of “social” behaviors on social media platforms, such as liking or sharing.<sup>107</sup> Such presumptions underlie much psychological work on autistic youth media use. For example, in their study “Prevalence and Correlates of Screen-Based Media Use Among Youths with Autism Spectrum Disorders,” clinical psychologist Micah Mazurek and her colleagues write that a majority of autistic 13- to 17-year-olds in the United States “spent most of their free time using non-social media (television, video games)” while less than a quarter of them “spent time on social media (email, internet chatting).”<sup>108</sup> Compared to children with intellectual disabilities, learning disabilities, and speech and language impairments, autistic children used social media less and non-social media more.

While it may be a clear-cut distinction from the purview of clinical psychology, deeming one type of media social and another nonsocial is difficult to do within media and cultural studies, where it is understood that people make all kinds of media—including television and video games—socially

meaningful through their shared practices and experiences.<sup>109</sup> Communication scholar James Lull, for example, highlights how TV has structural uses, in that it can shape the flow and organization of human behavior in various settings, as well as relational uses, in that it may facilitate or curb communication, social learning, and interaction.<sup>110</sup> Video game play is often presumed to be solitary and separate from social engagement with friends and family, but this is rarely the case, especially for autistic children.<sup>111</sup> The claim that young people on the spectrum choose less immediately socially interactive media due to their supposed social impairment is problematic because it makes an essentialist argument about the relationship between autism and sociality that somehow exists outside of technology. Instead of starting from the socially determinist assumption that autistic people are asocial or antisocial, or the technologically determinist idea that television or any other kind of media is inherently social or antisocial, STSS asks how media and technology directly and indirectly impact how people learn to participate in and contribute to society and the meaning of sociality itself.

## MODERN AUTISTIC CHILDHOODS

Autistic children are rarely understood to be social actors or recognized as engaging in social activities, which in turn impacts how they express themselves socially through media and technology. For kids on the spectrum, the failure to follow unwritten implicit social codes of the neurotypical majority has psychosocial consequences. Frustration arising from unsuccessful social exchanges, pressure to conform to neurotypical expectations, and peer victimization can all lead to negative mental health outcomes, such as depression and anxiety.<sup>112</sup> When young people on the autism spectrum enter the complicated landscape of adolescence, research has shown that they express a desire to connect with their peers but end up infrequently participating in social activities or hanging out with friends outside of school.<sup>113</sup> Self-help books with titles like *The Asperkid's (Secret) Book of Social Rules* are written with the aims of helping autistic adolescent audiences master etiquette in order to prevent future harms.<sup>114</sup> Many participate in school-based intervention programs that are focused on social skills.<sup>115</sup> Some researchers have argued, however, that these programs center the neurotypical communication preferences of therapists and that social programs built around shared interests are more effective.<sup>116</sup>

The social challenges that autistic children face occur among the broader conditions of contemporary childhood, within which media and technology are increasingly central. Today's young people on the spectrum might have much in common with past generations of autistic individuals who are now adults in terms of their social, emotional, and sensory needs. It is important to recognize, though, the differential influence of growing up in the hypermediated twenty-first century. There are important distinctions between the experiences of older autistic adults and autistic children today that are borne of the latter coming of age following passage of the Americans with Disabilities Act (ADA) of 1990. The ADA resulted in legal and cultural shifts toward greater (yet not full) inclusion, leading disability rights activist Rebecca Cokley to coin the term "the ADA generation."<sup>117</sup>

Modern communication technologies also impact multiple interconnected layers of children's lives inside and outside their homes. This encompasses, for example, a child's use of a Google Chromebook for homework, Google's data policies in school districts, and a lack of legal regulation of Alphabet, Google's parent company.<sup>118</sup> Dynamic understandings of the relationship between society and technology also extend to the level of the individual, meaning that children and adolescents both act on and are acted upon by sociological and technological forces. For instance, machine learning algorithms embedded in search engines and recommendation systems for streaming video content on YouTube or Netflix may have a disproportionately negative impact on autistic children, and in more than one way. These technological features could make it difficult for those who have challenges with top-down executive functioning to set their own time limits on media use; those with cognitive challenges might have difficulty understanding the persuasive intent of digital advertising, marketing content, and political propaganda.<sup>119</sup> The STSS approach incorporates transactional and ecological system perspectives on autism and human development,<sup>120</sup> which emphasize how autism is not a static entity and that the social influences on any one autistic person are multilayered across their immediate social environments and the wider sociocultural context.<sup>121</sup>

## AUTISTIC CHILDREN AND "SOCIAL" TECHNOLOGIES

Children on the spectrum reportedly spend more time with screen-based media than any other leisure activity, averaging about four and a half hours

per day.<sup>122</sup> Research on their media use is largely clinically oriented and centered on correcting deficits in the individual child, framing their social expression as more biomedically determined than contextually dependent.<sup>123</sup> However, when applied to autistic young people and their use of technology, being social has multiple meanings. This includes research on how media purportedly promote harmful *antisocial* behavior and exacerbate *asocial* self-isolation, the development and deployment of instructional technologies intended to *socialize* autistic children, and media that autistic children adopt and appropriate for their own *socializing*.<sup>124</sup> What makes a technology a “social technology” is negotiated across these different categories. The STSS perspective highlights how these varied framings of sociotechnical dynamics shape one another as well.

A focus on asocial behavior is reflected in work on curbing improper screen use and problematic addiction.<sup>125</sup> Negative media effects measured in such studies include autistic children’s diminished ability to read facial expressions, lower friendship trust, and feelings of alienation.<sup>126</sup> Some research suggests that children on the spectrum prefer interactive media because it is more predictable and easier to control than social or environmental stimuli, which are often unpredictable.<sup>127</sup> Far less work has examined media’s positive psychosocial effects on them.<sup>128</sup> The majority of published research on the harms of screen and interactive media for autistic children has been on television and video games. Autistic adolescents report a preference for video games over other leisure activities<sup>129</sup> and spend on average one hour more per day playing them than their typically developing peers.<sup>130</sup> Little of that time with video games is reportedly spent on social interaction.<sup>131</sup> Even within games that contain some opportunity to interact with others, online exchanges can lead to negative social consequences like cyberbullying and online harassment, which are further exacerbated by challenges that autistic children may encounter in registering emotional cues.<sup>132</sup> These reports on overall media use also reflect the gendered skew of autism research and higher rates of video game use among boys.<sup>133</sup>

When autistic children are encouraged to use technology by teachers, therapists, and counselors, it is often with the purpose of having them more fully adapt into neurotypical society. Apps, robots, and other socialization tools encourage social learning and imitation, with the goal of assisting autistic children by reducing anxiety or uncertainty when encountering novel social situations.<sup>134</sup> These digital media emphasize specific goals such as

teaching children turn-taking in play, rules in games, and reciprocity in face-to-face conversation. However helpful they might be, these technologies are often implicitly or explicitly designed to make children appear “less autistic” in their communication and behavior.<sup>135</sup> They are rarely designed to support nonautistic young people in how they communicate and socialize with their autistic peers or the interdependence between people with and without disabilities.<sup>136</sup>

Socialization technologies span a wide range of philosophical intentions. Virtual reality has been used to teach autistic children to recognize body language, register facial expressions, and gauge emotional environments in a customizable digital simulation. Studies have shown that virtual reality can aid autistic children in adapting to pretend play situations with a peer.<sup>137</sup> Robots programmed to predictably perform simple social interactions, based on the principles of cognitive behavioral therapy and applied behavior analysis,<sup>138</sup> have similarly been used to practice joint attention, reading facial expressions, and initiating conversations.<sup>139</sup> Wearable devices like Google Glass are also being deployed with autistic children. Through speech recognition algorithms, spoken words can be translated into text and paired with a social response, then projected onto the lens of the glasses in the user’s line of sight.<sup>140</sup>

Educational, therapeutic, and medical technologies for autistic socialization come with a host of limitations, including a lack of empirical support even if one accepts their rationale.<sup>141</sup> Critics contend that some of these technologies treat autistic children like machines and perpetuate Bettelheim’s framing of them as robotic and inflexible in their movement, language, and emotions.<sup>142</sup> It should be noted that some autistic people, most famously the animal behaviorist Temple Grandin, describe their thought processes in technological terms or “thinking in pictures,” the title of Grandin’s 1995 book.<sup>143</sup> The focus on autistic minds as computers, though, can overshadow other helpful interventions. There is strong evidence that art, nature, and animal-based therapies are enjoyed by autistic children and can similarly support social interactions by reducing anxiety.<sup>144</sup> Yet funding for “innovative” research tends to go toward new gadgets.<sup>145</sup> Therapeutic technologies are generally geared toward a particular kind of sociality, which does not necessarily include the kinds of social activities, interactions, and relationships that autistic individuals indicate that they desire.<sup>146</sup> Teaching children that sociality can be followed like a script also raises ethical issues regarding compliance and agency.<sup>147</sup>

Taken together, the asocial, antisocial, and digital socialization framings of autistic children and their media use underpin the pervasive belief that screens must be educationally or therapeutically beneficial in order for them to be worthwhile. This imbalance is reflected in the lack of research on autistic youth's digital socializing, which takes place in physical and virtual social spaces where there is a digital presence. It involves digital tools designed for and by autistic people as well as those that youth on the spectrum like Adrian adapt for social purposes.<sup>148</sup> For example, autistic tweens, teens, and young adults like influencer Chloé Hayden have taken to the musical social media platform TikTok to change public perceptions of autism, partly in reaction to the ableism perpetuated on the app.<sup>149</sup> Through their digital ethnographic work, Kathryn Ringland and colleagues have studied Autcraft, a private Minecraft server that provides a supportive space for autistic children to play in the virtual world.<sup>150</sup> The Autcraft community works with the strengths that autistic children have while also being responsive to realistic challenges. Young people with disabilities ought to be able to enjoy the pleasurable aspects of digital play and performance regardless of any measurable clinical benefit.<sup>151</sup>

## ACROSS THE (AUTISM, MEDIA, AND SOCIOECONOMIC) SPECTRUMS

Besides engaging with a full range of media in this book, I center the stories of children who not only are on the autism spectrum, but who also come from vastly different socioeconomic, racial, and ethnic backgrounds along with other aspects of human difference. The STSS perspective attends to the different ways in which social groups are historically marginalized in society. The study of autism is inherently incomplete based on who does and does not have access to a diagnosis. This book is no different, as illustrated by the story of Monisha and her three sons Orion (age 4), Kahlil (age 7), and Clayton (age 8). Monisha is a single Black mother without a college degree who, when I met her in the summer of 2019, was trying to find work as a home health aide. She and her sons lived in an apartment subsidized through the Section 8 rental assistance program for low-income households.

I first interviewed Monisha on a hot June day in Boston. She wore a black tank top, and I immediately noticed, on her upper right arm, a large tattoo of three interlocking puzzle pieces, each containing the name of one of her sons. Puzzles are an object of children's play, but puzzle pieces have also

become a ubiquitous symbol of autism.<sup>152</sup> Monisha verified that her tattoo was “kind of autism inspired.” What primarily interested me about the tattoo, though, was that only two of her children, Orion and Kahlil, were diagnosed with autism. Older brother Clayton was part of Monisha’s tattoo but not technically eligible for my study because he did not (yet) have an autism diagnosis. The reason for his exclusion reveals how autism is never one spectrum, but multiple.<sup>153</sup> Race, class, and ableism work in tandem; in the United States, more than half (56 percent) of autistic children live in poverty, whereas, of the children not on the spectrum, the rate is 42–47 percent.<sup>154</sup>

What we know about autism and autistic children is heavily influenced by who gets counted in the first place.<sup>155</sup> In the United States and other industrialized countries, the number of children with a diagnosis has been on the rise since researchers first began systematically tracking autism in the early 2000s. Among children, the Centers for Disease Control and Prevention (CDC) estimates that one in forty-four 8-year-olds had an autism diagnosis in 2018, up from an estimated one in 166 in 2005.<sup>156</sup> The National Center for Education Statistics reports that autistic children ages 3 to 21 comprised 11 percent of disabled school children in the United States in 2019–2020 but 1.5 percent in 2000–2001.<sup>157</sup> However, scientists are largely in consensus that the overall prevalence of autism has risen due to greater awareness, improved monitoring, and changes to diagnostic criteria. For instance, it was only in 2006 that the American Academy of Pediatrics began to recommend screening all children for autism during routine pediatrician visits at 18 and 24 months.<sup>158</sup>

If anything, official counts of autism diagnoses are underestimations. Diagnosis rates in the Global South are low due to cultural stigma and gaps in the recognition, interpretation, and reporting of autism.<sup>159</sup> In the United States, significant disparities remain even though widespread screening has led to improved detection among underrepresented groups.<sup>160</sup> CDC data shows that Latino children are identified with autism at lower rates than are Black or White children. This is due to several factors, including culturally and linguistically inappropriate clinical care.<sup>161</sup> White children regularly stand in for all children in autism research because many studies fail to even report the race or ethnicity of research participants, rendering non-White kids doubly invisible.<sup>162</sup> Boys are four times more likely than girls to receive an autism diagnosis, reflecting historical gender biases in the construction and delivery of autism assessments.<sup>163</sup> Children who live in urban geographic



areas with a higher concentration of clinical services are also more likely to receive a diagnosis than those in underresourced rural regions.<sup>164</sup>

At the moment, Clayton did have a diagnosis—but of “emotional behavioral disorder.” Monisha thought that he had been misdiagnosed and was trying to make a doctor’s appointment to get him reevaluated. “They don’t want to diagnose him with [autism] because they felt like he was on the border with it,” Monisha shared, “but some of the similarities [between Clayton and his brothers] I see too.” In the United States, Black boys like Clayton are statistically more likely to be misdiagnosed prior to receiving an autism diagnosis and are disproportionately diagnosed with emotional disturbance.<sup>165</sup> Black children also receive autism evaluations and resulting support services at older ages than White children.<sup>166</sup> Those like Clayton who do not have an intellectual disability are diagnosed with autism at lower rates than are White children.<sup>167</sup> Labels like emotional disturbance have also long been used to pathologize the trauma produced by racism that Black people endure.<sup>168</sup> Autism has historically been the domain of White, upper-middle class boys ever since it was first studied in the United States and Europe at the turn of the twentieth century.<sup>169</sup>

While Adrian’s mom, Brianna, had access to a set of vocabulary from which she could comfortably refer to Adrian as an “Aspie,” Monisha’s tattoo was an indelible claim to the same for Clayton, written in ink on her arm instead of with a pen on a clinician’s notepad. Parents—especially mothers—contend with major challenges in managing the complex bureaucracies of health care and education that present difficulties for children with often “invisible disabilities” like ADHD and autism.<sup>170</sup> Clinical and diagnostic uncertainty means that children and adults may receive multiple diagnoses that shift over time. In some cases, additional disabilities may accompany autism (such as intellectual disability, language delay, and anxiety), which complicates how autism is treated as well as singled out to be diagnosed.<sup>171</sup> Receiving one or more diagnostic labels can also unlock services like occupational and sensory integration therapy for those who know to advocate for them. The structural inequalities embedded in these systems are compounded for single mothers and for caregivers raising children of color, and acutely so for those in both groups like Monisha.

My inability to formally count Clayton in this study because, unlike all of the other children, he did not have a diagnosis at the time, speaks to the

complex racial inequalities around autism and how multiple forms of marginalization, stigmatization, and discrimination underpin all discussions of social institutions. Clayton was struggling socially, emotionally, and behaviorally, and an autism diagnosis might lead to him getting the right kind of support—the kind that Adrian was receiving with a significant investment of energy, advocacy, and money from his parents. “When he tries to make friends,” Monisha said of Clayton, “I notice a lot of kids just sitting back observing because he’s real loud [and] he doesn’t really get the pitch in his voice,” an auditory processing issue that can be a sign of autism.<sup>172</sup> Like Adrian, Clayton could get overwhelmed by small stressors like homework, leading to tears and anger. His social and emotional challenges were also compounded by physical bullying that was largely ignored by staff at his school, which prompted Monisha to move to a better school district just outside of Boston.

As did Adrian, Clayton showed a real aptitude for art and an interest in the complexities of the Pokémon universe and media franchise. While we sat in his living room during my observational visit, Clayton made multiple trips to his bedroom to retrieve and show me one highly detailed Pokémon illustration after another. “I’m trying to draw all the 151 Pokémon from Gen 1,” he said, proudly laying his colorful Bulbasaur, Ivysaur, and Venusaur character drawings out on the sofa (figure 1.1). Clayton said that he had learned how to draw Pokémon by studying YouTube tutorials. “When I grow up,” he stated matter-of-factly, “I’m going to be a very social artist.” At the moment though, Clayton’s ability to become “a very social artist” was limited by educators and clinical professionals who could not piece together that he was likely a Black child on the autism spectrum.

While Clayton and Adrian illustrate differences between families of autistic children, Clayton and his two brothers demonstrate the variations that can exist within the autism spectrum. Their neurodivergent profiles and media interests were similar yet dissimilar. Clayton and Orion enjoyed playing together on the video game platform Roblox from their respective tablet computers. Kahlil liked to listen to music on Monisha’s old phone, holding the speaker to his ear while walking around the apartment on the periphery of his brothers’ play. Clayton was very talkative, Orion was just starting to gain more confidence speaking after receiving in-school speech therapy, and minimally speaking Kahlil was recently issued an AAC device to communicate with in class, though Monisha said that he would sometimes sing

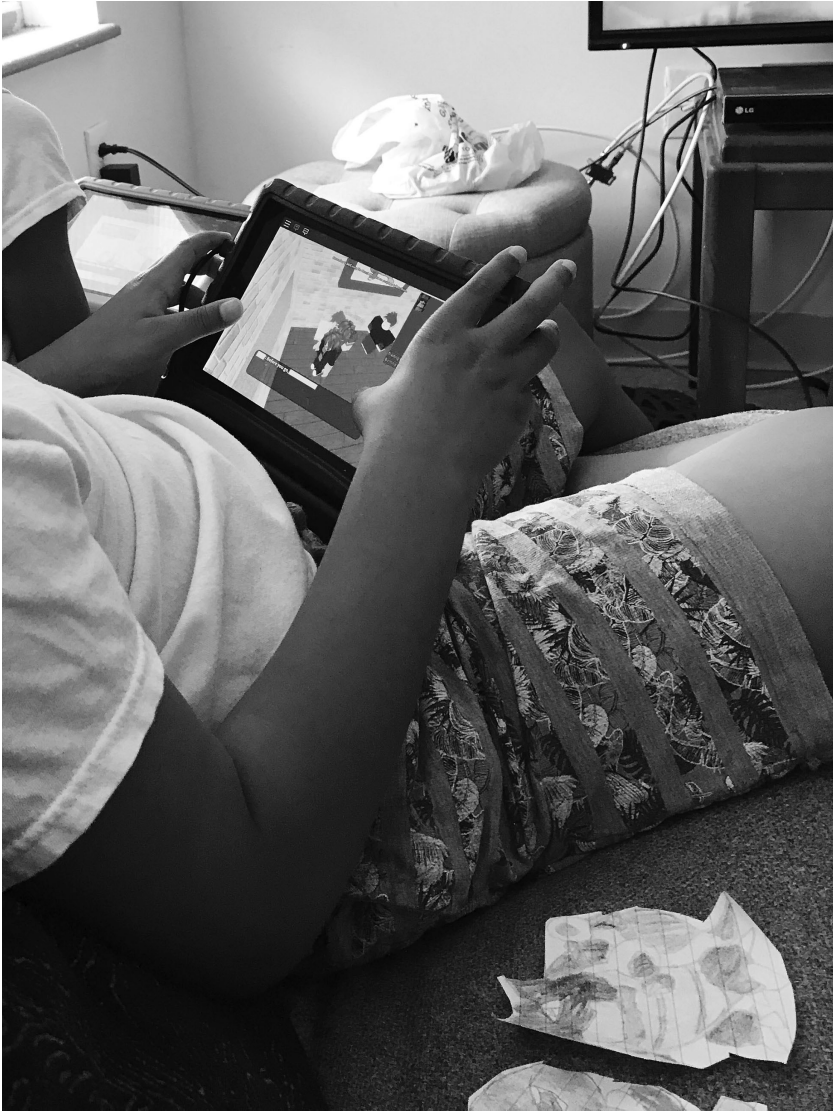


FIGURE 1.1

Clayton (*front*) and Orion sit side by side on the sofa, playing video games on their respective tablets with a movie on the television set in the background. Clayton's Pokémon drawings are beside him. *Source:* Meryl Alper.

to himself or along with YouTube music videos. The story of Clayton and his brothers illustrates how being autistic does not explain everything that a child does with media—in fact, it might only account for a small portion.

## STUDY OVERVIEW

For this book, I employed a range of research methods that allowed for deep inquiry with autistic children and their families (see the Appendix for a further explanation). Fifty-eight households took part; in total, there were sixty-two children, including four sets of autistic brothers. I interviewed parents—mostly mothers, but sometimes fathers and couples—about their family life and the benefits and challenges of their autistic child's media use. The average child was approximately 7 years old at the time of the initial parent interview. With this background information, I returned to the homes of fifty-three kids to observe them engaging in a favored media activity, sometimes solo or with family members. Because they are rarely considered experts on their own lives,<sup>173</sup> I interviewed eighteen speaking autistic children between the ages of 6 and 13 years as part of my return visit. I also reinterviewed and reobserved a handful of children and parents a year later and, in one case, five and a half years later, in order to gain longer-term perspectives.<sup>174</sup> This recontact work stretched into the start of the COVID-19 pandemic in April 2020, though my fieldwork did not continue further into that tumultuous year. Twenty-six children in the study, or a little over 40%, had a communication impairment. I was able to conduct a remote asynchronous interview with one nonspeaking child in which their parent wrote down and sent back responses to my questions that the child answered by pointing to letters on a letterboard. Many were too young to be interviewed, did not use their AAC device regularly at home (if they had one to begin with), or were not receiving adequate speech-language therapy services to support their ability to be interviewed.

The most upsetting example of this was 8-year-old Saaida, who did not speak, who had no assistive communication system, and whose development was severely impaired due to lead poisoning from paint chips in the apartment that her family first rented when they moved to Boston from Bangladesh. While Saaida's father had mentioned in our initial interview that they did not keep paper of any kind in the home because Saaida liked to eat it, I made the mistake of bringing a small notebook with me to

the follow-up observation. When I would not give her the book after she lunged for it, she yanked my hair and bit my arm, forcing me to end the observation early. Being able to be interviewed for this book—be it through spoken, written, or symbolic language—is in some ways more a marker of privilege than the absolute ability of an autistic child. It was important to include children like Saaida—nonspeaking, non-White girls from the Global South—because they rarely make an appearance in autism research.

In recruiting families for the study, I employed what Lindlof and Taylor term “maximum variation sampling” in order to study children and families from many possible angles.<sup>175</sup> Through a variety of methods, I purposively recruited more children of color and those from poorer and lower income families than are generally included in autism research. A little more than half were from families that earned less than \$100,000 annually ( $n=33$ ) and a little less than half earned more ( $n=29$ ). Ten were from families earning less than \$25,000 a year. Some children lived in spacious houses, others lived in small apartments, and yet others were housing insecure. Half were non-White ( $n=31$ ) and half were White ( $n=31$ ). The sample skewed more toward children who identified as boys ( $n=44$ ) than those who identified as girls ( $n=18$ ), but it is still more gender balanced than the available distribution data on autism. The study enrolled at least one transgender child and one parent who identified as genderqueer.

These young people had much in common besides an autism diagnosis. They lived in Los Angeles or Boston—progressive coastal cities and industry hubs that were resource rich but deeply segregated. Both cities were near sites of world-class medical care yet also grappling with severe income inequality. Media and technology were also a clear commonality among them. Many parents allowed their children to watch YouTube with minimal restrictions, and most did not know of or chose not to use the supposedly more age-appropriate YouTube Kids app. Streaming video sites like Netflix were readily adopted, though less well-off families were more likely to gain access through accounts shared with friends. Young children consumed a lot of educational PBS KIDS programming, while older children were drawn to YouTube personalities. Across households, nearly all children and parents had their own personal mobile devices, be it a phone or tablet, a broken hand-me-down or the latest model.

## BOOK OVERVIEW

In the pages that follow, I detail how autistic children's experiences with media converge and diverge with those of neurotypical children and of each other in three main ways: (1) *cultural belonging* through their identity development and learning (chapters 2 and 3), (2) *social relationships* among their family and friends (chapters 4 and 5), and (3) *physical embodiment* in terms of their sensory and emotional processing (chapters 6 and 7). These themes and topics touch upon concerns for all children and adolescents in the digital age, namely the relationship of social-emotional development to other developmental domains (e.g., physiology, cognition) and the myriad cultural, political, and historical factors shaping childhood.<sup>176</sup> These themes also overlap, such as in how autistic children's use of media for emotional expression is influenced by their interactions with peers and family members.

Chapter 2 looks at how children on the spectrum come to understand themselves, their autism, and its intersections with their race, ethnicity, and gender *identity* through the media content they create, consume, and share. Some autistic kids find their identities reflected in popular media characters that are implicitly and explicitly disabled, and others create opportunities for identification through the avatars they design and the comics they illustrate. Parents can be a critical part of their child's identity formation and sense of belonging cultivated through their media use. Autistic parents and other adult role models on the spectrum may be especially useful by providing valuable guidance.

Chapter 3 addresses the potential for autistic children's informal *learning* with media at home against the backdrop of struggles to access a fair and appropriate public education, particularly in under-resourced schools. Much has been made of using flashy gadgets to teach autistic children social skills, but little work explores their families' preexisting values, routines, habits, and beliefs about media, technology, and learning.<sup>177</sup> Outside the classroom, digital media allows many autistic children to pursue their interests and hobbies as well as to engage in self-directed and self-paced learning in areas like reading and math, social and communication skills, and creative expression. However, these very platforms also put autistic children at a heightened risk for privacy and safety violations.

Chapter 4 focuses on the ways that media and technology become central to relationships, bonds, and intimacies between autistic children and

their parents, siblings, and extended *family* members. Parents make constant tradeoffs to promote benefits and prevent harms to their children in the long and short term. Media is central to this negotiation, with the outcomes more or less successful not only because of the decisions that individual parents make, but also because of infrastructural and institutional issues like poverty and social media platform policies beyond their immediate control. The extreme uncertainties facing households disproportionately impact families of children with disabilities.<sup>178</sup> These pressures manifest in the outsized role that media plays in many of these young people's lives, as well as those of their family members.

Chapter 5 extends the discussion of relationships to autistic children's mediated *friendships* with neurodivergent and neurotypical peers. This chapter looks at the positive and negative aspects of social interactions between autistic kids, their classmates, and online friends, and how those connections and tensions are shaped by popular culture, media, and technology. Autistic children's friendships are co-constructed by the normative social affordances of communication technologies, as well as by broader societal forces that often limit the physical and digital spaces available to these young people.

Chapter 6 draws attention to how embodiment and *sensory* processing shape autistic children's social interactions through and around media and technology. Media is often thought of as stimulating external senses, like sight, hearing, and touch, but internal ones, like body awareness and movement, are less often considered in that context. This chapter takes an integrated approach to how autistic children experience a full range of pleasurable and painful sensory stimuli and how their experiences shape domestic spaces, intimate relationships, and family practices during media use. Autistic children and their caregivers often alter the immediate media environment around a child to meet their sensory needs, but families with less financial resources have diminished control over the built world in general.

Chapter 7 examines the ways that mass media and communication technology impact how autistic kids recognize their own internal states, specifically the ways that their *emotions* and behaviors are read by their social partners, and how technologies come to interpret their feelings and actions. Digital technologies used to treat and identify signs of autism (e.g., algorithms, apps) operate from a very simple notion of emotion, namely that autistic people cannot identify the emotional states of others or their own.<sup>179</sup> This chapter illustrates the depth and complexity of autistic children's affective states and

examines how media technologies could better account for these expressions and interpretations. Also discussed are the wider ethical and design implications for emotion and behavioral recognition technologies.

Lastly, chapter 8 concludes by pointing toward new directions for understanding sociality and social technologies and for supporting autistic children and adolescents in the digital era. This chapter incorporates the reflections of young people on the spectrum and their parents at the beginning of the COVID-19 pandemic. I discuss implications of the book's findings for the education, health-care, and technology sectors, offered with the goal of guiding more effective efforts toward equity, access, and justice for autistic kids at home, at school, and in their communities.

Broad-stroke discussions about autism, technology, and kids look very different up close if you pay attention to what seems like minor details in the aggregate. Nondisabled and neurotypical people have much to learn if we are to build a more resilient and compassionate world. There is an adage that goes, "If you've met one person with autism . . . you've met one person with autism," which is a twist on the pejorative phrase, "If you've met one person [insert description], you've met them all." The revised phrasing is meant to highlight the complexity of autism, but even the more inclusive version can be too focused on the level of the individual. "One person with autism" is also someone shaped by their physical environment, social context, and historical factors, and is an individual who inhabits a body that is seen by others as having a race, ethnicity, gender, and sexuality. If you've met only one autistic person, you really should meet more, starting with the next chapter.





© 2023 Massachusetts Institute of Technology

All rights reserved. No part of this book may be reproduced in any form by any electronic or mechanical means (including photocopying, recording, or information storage and retrieval) without permission in writing from the publisher.

The MIT Press would like to thank the anonymous peer reviewers who provided comments on drafts of this book. The generous work of academic experts is essential for establishing the authority and quality of our publications. We acknowledge with gratitude the contributions of these otherwise uncredited readers.

This book was set in Stone Serif and Stone Sans by Westchester Publishing Services, Danbury, CT.

#### Library of Congress Cataloging-in-Publication Data

Names: Alper, Meryl, author.

Title: Kids across the spectrums : growing up autistic in the digital age / Meryl Alper.

Description: Cambridge, Massachusetts : The MIT Press, [2023] | Includes bibliographical references and index.

Identifiers: LCCN 2022033238 (print) | LCCN 2022033239 (ebook) | ISBN 9780262545365 (paperback) | ISBN 9780262373999 (epub) | ISBN 9780262374002 (pdf)

Subjects: LCSH: Mass media and youth. | Technology and youth. | Autistic children. | Youth with disabilities.

Classification: LCC HQ799.2.M352 A47 2023 (print) | LCC HQ799.2.M352 (ebook) | DDC 302.23083—dc23/eng/20221212

LC record available at <https://lcn.loc.gov/2022033238>

LC ebook record available at <https://lcn.loc.gov/2022033239>